

File No. R-18/12/2020-PRPP (RU-3)

NATIONAL HUMAN RIGHTS COMMISSION

Dated: 23rd July, 2021

Subject: Minutes of the Presentation on Leprosy and Leprosy Colonies/ Homes, held on 20.07.2021 in Room No. 508

A PowerPoint presentation was held on the captioned subject on 20th July, 2021 at 11:30 am, in Room No. 508. The discussion was chaired by the Hon'ble Chairperson Justice Shri Arun Kumar Mishra, and co-chaired by Justice Mahesh Mittal Kumar, Member, NHRC. Two experts joined the meeting via Cisco Webex, Dr. Vineeta Shanker, former Executive Director, Sasakawa-India Leprosy Foundation and Ms. Nikita Sarah, Head of Advocacy and Communication, The Leprosy Mission Trust India. The list of participants is enclosed at Annexure-I.

2. At the outset, **Shri R.K Khandelwal**, Additional Secretary, NHRC welcomed all the participants and briefly spoke about the importance of the subject and the need for deliberations on the same. He briefly mentioned about the main topics to be covered in the presentation.

3. The presentation was made by **Ms. Aakanksha Sharma**, Junior Research Consultant, NHRC. The major headings included in the presentation for further discussion are:

- Introduction to Leprosy
- Global status of Leprosy
- Status of Leprosy in India
- Additional Initiatives taken up by NHM, India, from 2020
- Leprosy and Human Rights
- COVID-19 and Leprosy
- Leprosy colonies
- Issues to address
- NHRC's past initiatives
- Way forward

4. **Dr. Vineeta Shanker** emphasised how Leprosy is a neglected disease and the fact that the pandemic has shifted our attention to other areas than Leprosy issues. She suggested that there is a need to make efforts in a mission mode if we want a change by 2030. She said that we always talk about people living in leprosy colonies, but we also need to pay attention to people affected by Leprosy living outside these colonies as well.

According to her, in the fight for human rights, both medical intervention and intervention for socio-economic empowerment and integration in society is crucial. The contours of the implementation are there (various schemes and policies of the Government), but the issue lies with the lack of access and improper implementation. She mentioned that while people living in leprosy colonies were getting food supply during the pandemic, what was more critical was lack of financial and medical assistance.

She also shared that some leprosy colonies are very well organised with good leadership examples, which definitely gives a ray of hope. As a response to HCP's question regarding the good qualities of those leprosy colonies, she said that it is threefold; one, good leadership; two, State level intervention, which involve the eagerness of local level authorities to help these people so that they can facilitate the interaction and integration of the colonies with the existing schemes like Ayushman Bharat, etc. and three, the work of CSOs and NGOs.

5. **Hon'ble Chair person, Justice Shri Arun Kumar Mishra** raised an important concern that when there is medical advancements and the disease is treatable, then why do these people still live in colonies and not integrated in the society itself. He emphasised that the States need to conduct a study to know how many leprosy cases are being reported every year to know the prevalence of the disease and get the data of number of the colonies of leprosy affected persons and the number of people living there in. He stated the fact that the ground reality of the conditions of leprosy colonies and the livelihood conditions, including socio-economic ones, are significantly neglected. In the end, he asked the experts for the relevant statistical data to be shared via email so that further necessary actions could be taken.

6. **Justice Mahesh Mittal Kumar, Member, NHRC** asked the experts that how many people affected by leprosy have gone back to the mainstream after getting treated. It was discussed that these people are not going into the mainstream. As the severe cases are declining, the need to hide the disability is also lesser in the new cases detected. And if they do have severe deformity, they don't go out of the house but at night, due to the stigma attached, which is another big challenge in context of leprosy.

7. **Ms. Nikita Sarah** shared that it is estimated that there are 2 Lakh people living in Leprosy colonies and 76 rehabilitation centres for people affected by Leprosy. She also corrected that the word Leper/ Leper home is no longer used as it is very derogatory. She shared that every year 1.15 lakh new cases of leprosy, however, very minuscule are from the leprosy colonies. The moment a person gets diagnosed with leprosy, severe stress is seen in them, that also leads to increased prevalence of clinical depression amongst people affected from leprosy. Since there are numerous myths about leprosy, awareness programmes are very much needed, according to her. There is a need to repeal the still existing (99 in number) discriminatory laws in India.

8. **Important recommendations emerged out of the meeting are:**

- There is a need to redraw the focus of the States on the importance of addressing Leprosy issues.
- Concerted efforts need to be made to sensitize and create necessary awareness among different stakeholders that leprosy is not a very contagious disease and that the people affected with it can be cured and can be integrated to the main-stream & co-habited with their families.
- There is a need for Psychological Counseling/ Mental health support for people affected by Leprosy, especially children.
- Drastic and concrete measures are required to be taken to ensure that the schemes and the funds meant for the welfare of leprosy affected persons and their colonies are implemented with all earnest and earmarked funds are utilized properly.
- There is a need to repeal the discriminatory laws against leprosy.
- There is a need to set up a committee of medical experts to review and appropriately revise the disability guidelines.
- Special attention must be given to most vulnerable population – women, children, elderly and residents of these colonies.
- Civil Society and NGOs also need to work more sincerely to ameliorate the cause of leprosy affected persons and to integrate their colonies with the mainstream of society.
- States need to conduct a study to know how many leprosy cases are being reported every year to understand whether the disease is declining or increasing in the country and to know the number of the colonies of leprosy affected persons and the number of people living there in.
- States need to appoint a nodal welfare officer to act as a bridge between the State machinery and the colonies of the leprosy affected persons to help them get benefits of the Government schemes.
- There is a need to focus on the education and counseling of the children of leprosy affected people to overcome the stigma and help them integrate with the mainstream of the society.
- It must be ensured that sanitation, water, electricity and other basic amenities including healthcare, financial assistance is provided to the leprosy affected people living in separate colonies.
- Skill development programmes must be initiated to train them and provide them with opportunities for their socio-economic empowerment to earn sustainable livelihoods with dignity
- States need to set-up a system of monitoring of funds given to NGOs working for the welfare of leprosy affected persons to ensure proper utilisation of funds.
- A welfare officer should be attached to the group of these people to know their livelihood and work on the awareness to eradicate stigma.

List of Participants

1. Justice Shri Arun Kumar Mishra, Hon'ble Chairperson
2. Justice Shri. Mahesh Mittal Kumar, Member
3. Shri Bimbadhar Pradhan, IAS, Secretary General
4. Shri R.K. Khandelwal, IAS, Addl. Secretary
5. Dr. M.D.S Tyagi, JD (R)
6. Shri Sudesh Kumar, SRO (R)
7. Ms. Aakanksha Sharma, JRC
8. Dr. Vineeta Shanker, Ex. Executive Director, Sasakawa India Leprosy Foundation
9. Ms. Nikita Sarah, Leprosy Mission India